

**A Case Study: Community-Based Managed Care Program for Alzheimer's and Other  
Related Dementias**

by

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**Abstract**

A shift from long-term senior care to community living for those living with memory disorders has necessitated an increase in comprehensive care management programs to address their diverse needs. Increased life expectancy comes with challenges as many older Americans with memory disorders are living with co-occurring chronic health conditions that directly affect their quality of life. As the fifth leading cause of death worldwide and rapidly increasing, dementia is slated to become a global health crisis by the year 2035, with cases in the United States reaching 14 million by the year 2060. To help combat this issue, Presbyterian SeniorCare Network created a memory-care specific managed care program called *Dementia360* to alleviate the burden of caregiving and increase the overall quality of life for memory-impaired individuals and their caregivers. *Dementia360* addresses care quality, access, and cost relating to the provision and sustainment of dementia care. This approach focuses on targeting public health-related challenges by drawing upon the *Triple Aim* framework developed by the Institute for Healthcare Improvement.

This essay aims to describe the managed care components of *Dementia360* to examine its model compared to others previously studied. Overall, *Dementia360* has created a framework incorporating best practices, thus strengthening the program's predicted success of achievable disease management.

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## Acronyms

Presbyterian SeniorCare Network (PSCN)

Person/People Living with Dementia (PLwD)

Institute for Healthcare Improvement (IHI)

Skilled Nursing Facility (SNF)

Continuing Care Retirement Community (CCRC)

World Health Organization (WHO)

National Institute of Health (NIH)

Perceived Quality of Life (PQoL)

Quality of Life (QoL)

Long-term Care (LTC)

Long-term Care Facilities (LTCF)

Primary Care Physician (PCP)

Montreal Cognitive Assessment (MoCA)

Activities of Daily Living (ADL)

Instrumental Activities of Daily Living (IADL)



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## **1.0 Introduction**

In general, the distinction between Dementia and Alzheimer's lies within the use and definition of each term. Dementia is used to describe the overarching brain disease that is associated with cognitive impairment and decline, while Alzheimer's is used to describe one of the specific (and most common) types of dementia. Oftentimes both terms are used interchangeably to describe the same phenomenon, which will be the case for this essay.

Alzheimer's disease was responsible for roughly 122,000 deaths in 2019, ranking it as the sixth leading cause of death in the United States (Alzheimer's Association, 2019). Unlike many other diseases, scientists cannot link specific risk factors to the progression of Alzheimer's, or pinpoint definitive ways to prevent its onset. Yet, it is estimated that around 50 million people are living with this disease worldwide, with nearly 10 million new cases occurring each year (World Health Organization, 2019). One of the major dilemmas associated with Alzheimer's and other related dementias is the rate at which the disease goes undiagnosed – with many associating the signs and symptoms to that of normal aging. According to Alzheimer's Disease International, only one in four people with Alzheimer's disease have been diagnosed (2015). Furthermore, due to its affliction on later-life stage individuals, many of those affected by Alzheimer's disease also present with a wide variety of associated comorbidities. This association not only skews the true rate of mortality but also contributes to the misunderstanding of Alzheimer's disease as a whole.

Memory diseases have other challenges too, affecting the lives of those responsible for providing care to those individuals. The world refers to these people as caregivers, and they can be spouses, partners, siblings, relatives, etc., however, the main similarity is the importance in which is placed on these caregivers. Dementia is often a slowly progressing disease that increases

in severity over time. As individuals age further, it is common for caregiving to become increasingly difficult (National Institute on Aging, 2017). The stressors associated with increasing amounts of rigorous caregiving commonly affects the mental health of the caregiver and could potentially lead to the manifestation of physical symptoms such as skeletomuscular pains, migraines, and overall fatigue. However, it is important to note that the incidence and severity of these symptoms, as a direct product of caregiving, is relative to the caregiver's overall situation (Schulz, Beach, Czaja, Martire, & Monin, 2020).

The purpose of this essay is to describe the managed care components of a community-based managed care program called *Dementia360* to examine its model compared to others previously studied. Additionally, the analogous relationship between the caregiver and person living with dementia (PLWD) will be explored to address the public health importance related to providing community-based dementia care and alleviating caregiver burden.

### **1.1 Presbyterian SeniorCare Network**

Presbyterian SeniorCare Network (PSCN) is a not-for-profit, faith-based network offering living and care options to communities across Northern and Western Pennsylvania. Currently, it offers services such as rehabilitation, skilled nursing care, personal care, dementia care, independent living/continuing care retirement community (CCRC), hospice services, and palliative care. The network is comprised of 40 different locations and serves more than 6,500 seniors across 10 different counties. The mission of PSCN is to enrich the aging experience through person-centered service and living options.

### 1.1.1 Oakmont Campus

The Oakmont Campus is PSCN's flagship location and corporate headquarters. The campus is comprised of three separate entities outlined below:

- The Willows – short and long-term skilled nursing and rehabilitation community
- Westminster Place – personal care community
- Woodside Place – personal care community specializing in dementia and Alzheimer's care

When PSCN built Woodside Place over two decades ago, this community was among the first in the country to offer a holistic, in other words, a comprehensive care approach that meets the physical, social, and psychological needs of persons living with Alzheimer's disease and other related dementias. Since then, Woodside Place, now recognized as The Woodside Program, has been replicated nationally and internationally and remains the gold standard in dementia care. The facility and program are recognized as a Dementia Care Center of Excellence and is responsible for inspiring the idea of a community-based managed care model called *Dementia360* (D360).



**Figure 1: The Willows, Photograph provided by Presbyterian SeniorCare Network**



**Figure 2: Westminster Place, Photograph provided by Presbyterian SeniorCare Network**



**Figure 3: Woodside Place, Photograph provided by Presbyterian SeniorCare Network**

## **2.0 Background**

The following sections describe the relationship between dementia and its impact on caregivers. Furthermore, to serve as a reference for the remainder of this essay a summary of the importance of community-based managed care will be discussed.

### **2.1 Dementia and Caregiving**

Caregiving individuals have crucial responsibilities when tasked with providing support to persons living with dementia. This role is oftentimes assumed involuntarily which leads to frustration, anxiety, and anger (Avent, Rath, Meyer, Benton, & Nash, 2019). The effects of being a caregiver can be rewarding, however without the right mindset and tools for success the burden associated with providing care can soon become insurmountable. The unpredictable nature of the disease contributes to this difficulty too, as many of the physiological causes and behaviors are misunderstood (LaMarre & Kramer, 2019). Three separate studies conducted in 2009, 2017, and 2019 all cited the relationship between negative side-effects associated with caregiver burden, most notably high rates of psychological morbidity and social isolation. Furthermore, these studies outlined links to other factors such as physical ill-health and financial burden with increasing levels of caregiving need (Brodaty & Donkin, 2009; Cheng, 2017; Swartz & Collins, 2019).

The delicate yet intimate relationship between these two populations remains of concern, as one's behavior directly affects the outcomes experienced by the other. As levels of caregiver burden increase so do the rate at which burnout occurs. This has a direct impact on the perceived

quality of life (PQoL) and affects the overall quality of care being provided. As the conditions of care begin to diminish, so does the quality of life (QoL) for the PLwD. This negatively associated cycle continues in perpetuity severely altering the chance of a positive cohesive relationship.

## **2.2 Importance of Community-Based Managed Care**

As the average age of the population continues to increase, there is a greater emphasis placed on being able to remain home longer. This is explained as being able *to age in place* – essentially meaning to postpone the need for using long-term care (LTC) or a long-term care facility (LTCF) and its services. This shift comes with the increase in the number of services being available outside of a traditional setting and transforming the point of care to a community-based model. This model of managed care is accomplished by providing an early intervention mix of coordinated access and community-based supports (Institute of Medicine, 2002).

Recent research has shown the potential success of this model by prolonging the length of time a person is able to live at home, compared to those who are not enrolled in a community-based managed care program for dementia and Alzheimer's care (Samsus, Black, Bovenkamp, Buckley, Callahan, Davis, Gitlin, Hodgson, Johnston, Kales, Karel, Kenney, Ling, Panchal, Reuland, Willink, & Kyketsos, 2018). Furthermore, the research has shown that coordinated memory-care programs have the potential to delay disease progression and increase the overall quality of life for both the caregiver and PLwD by establishing a person- and family-centered coordinated care environment in which the caregiver can provide the continuum of dementia care for the PLwD while remaining in a familiar setting (Samsus et al, 2018). The likelihood of larger societal impacts has been cited as well, recommending a shift in the dementia care paradigm could



prove to be cost-beneficial to the overall healthcare system by decreasing the avoidable use of acute-care health services (Samsus et al., 2018). In this context, community-based managed care has the ability to positively impact and even transform the traditional way of providing memory-care. However, this care model presents a few challenges that need to be addressed to guarantee future success – mainly regarding the initial scalability, payment reform, and dissemination of available care programs and resources.

### 3.0 Literature Review

Formal managed care has been in practice since the late 1930s, with the overall goal being to satisfy the health needs of an entire population without using exhaustive clinical resources that contribute to high utilization and high costs. Since then, the philosophy behind these programs has changed slightly, placing a greater emphasis on increasing health information and the use of supportive services among members with severe chronic illnesses (Fox & Kongstvedt, 2013). The main reason for this being that individuals who live with chronic disease oftentimes account for higher healthcare utilization costs due to neglect of controllable behavior changes. By focusing on the socio-behavioral aspect of disease management, the hope is to alleviate some of the costs that could otherwise have been avoided.

A study published by The Pennsylvania State University in 1992, measured the perception of caregivers on available case management services in a community-based setting. The study explored the relationship between care-managed service offerings and the rate of utilization of those services among family caregivers. The overall goal of the study was to identify barriers of utilization and perceived satisfaction with care management services by surveying families of dementia patients and then analyzing the responses. The study reported that caregivers were fairly satisfied with the care management services and with their contacts in the case management programs (Malonebeach, Zarit, Spore, 1992). Upon the conclusion of the study, caregivers reported that the connected services were *helpful* and *effective*. The caregivers also provided their concerns and challenges with the program, stating that they believed 1.) there were not enough services and 2.) the quality of care associated with personal in-home care and respite care were both inadequate. Additionally, another theme arose surrounding the perceived control of how the

services were delivered. The participants stated that they would specifically enjoy better control over who was providing the care, citing instances of disapproval towards the unqualified and ill-trained staff of the contracted agencies. Finally, the last conclusion identified was the desire to arrange services directly in order to be more involved in the care plan.

The study suggests that these issues could be solved by offering a menu-like care plan option in which it would empower the caregiver to make choices more freely instead of following the plan of a care manager who may not completely understand the situation. Finally, the study suggests increasing the information given to the caregiver so that they can be more informed when making decisions about appropriate care for the PLwD.

Later in 2003, a study was done to demonstrate the effectiveness of a managed care intervention for caregivers and the PLwD. The goal was to measure outcomes of clinical use of the PLwD and caregiver burden by establishing an experimental relationship between a managed care organization and the Alzheimer's Association, where both entities collaborated to offer structured care management with disease-specific expertise (dementia and Alzheimer's). The study lasted for one year and reported on its outcomes after 12 months. Initial findings reported that this collaboration proved to be successful as the clinical utilization rates among the PLwD dropped for those enrolled in this program compared to those who were not (Bass, Clark, Looman, McCarthy, & Eckert, 2003). Furthermore, caregivers reported increased satisfaction with the service suggestions and offerings compared to those who were seeking dementia services on their own. Finally, caregivers reported lower self-reported depression scores and symptoms compared to those who were not receiving assistance from the partnership. Overall, the study's results concluded that the collaboration was beneficial for both caregivers and the PLwD as the analyzed data proved to be statistically significant. Some limitations the authors noted were the

generalizability of caregiving situations, the level at which families accept the services being offered, and the lack of medical information concerning disease progression. Addressing these issues would have allowed for further clarification surrounding the impact of care consultations and overall reported effectiveness of the care management demonstration outlined in this study.

## **4.0 Dementia360 Program**

The *Dementia360* (D360) program is designed to bring the dementia-specific expertise from Woodside Place out into the community. PSCN calls this the Woodside Philosophy and is based on 25 years of innovation in dementia care leading to its designation of a Dementia Care Center of Excellence. This program focuses on two important aspects of dementia care management outlined below:

- 1) Provide the caregiver with a network of coordinated care access points for them and their loved ones to utilize in a community and home care setting
- 2) Assist with managing chronic health conditions and other comorbidities in addition to dementia

Through this dual-faceted approach, the program's goal is to decrease caregiver burden and provide greater QoL so that the caregiver can then provide seamless ongoing care to the PLwD. The program aims to accomplish this goal by assigning enrollees a care manager from whom they receive specifically tailored dementia care resources. The care manager also works as a peer navigator by assisting the enrollees through the caregiving process and helps them traverse somewhat complicated resource networks.

Currently, the program is granted funded until December 31, 2020, whereafter it will move to a fee-for-service payment model. Additionally, PSCN is partnering with a local insurance provider to minimize out-of-pocket expenses and provide greater coverage to their service users across Northern and Western PA. Currently, the total cost associated with program membership has not been established. PSCN states that pricing and total costs will be determined based upon

input from the local insurance provider. D360 was founded by PSCN in January 2019 and has operated one full fiscal year as of January 31, 2020.

#### **4.1 Eligibility Requirements**

Currently, the program is available to any caretaker or individual with memory impairment who lives within a 15-mile radius of PSCN - Oakmont Campus. Prospective enrollees then either express interest directly to PSCN, are referred by a friend/family member, or are referred by their primary care physician (PCP). A comprehensive overview of this information can be found in Appendix C. To be eligible for participation, the PLwD must continue to receive care in the home throughout their program enrollment without being placed in an LTCF. Additionally, the PLwD must have a diagnosis of some form of dementia or be working towards acquiring one. Finally, the PLwD must present with at least one other comorbidity other than dementia.

To fully participate in the program, interested caregivers are required to undergo an initial assessment or initial home visit where a care manager assesses the home, the caregiver, and the PLwD. During this visit, the care manager will conduct a caregiver observation, QoL questionnaire, and burden assessment using one qualitative method (recording caregiver observations) along with two quantitative methods (QoL questionnaire and standardized burden assessment). Samples of these tools can be found in Appendix A. Additionally, the care manager assesses the level of cognitive impairment, mental strain, and physical abilities of the PLwD through several quantitative methods using standardized assessments that require scoring in order to produce usable data to determine the base level of disease severity and overall abilities of the PLwD. Furthermore, these scored assessments assist with care management services procurement,

as it relates to choosing appropriate interventions based on the PLwD's disease state. Samples of these tools can be found in Appendix B. Following the initial meeting the care manager will schedule a second visit. After analyzing and identifying the main issues and concerns, a program roadmap will be provided consisting of suggested services, resources, and care options to explore. Thereafter the care plan will be amended and adapted as seen fit by the caregiver.

## **4.2 Cohort Characteristics**

As of January 31, 2020, there are 81 individual groups enrolled in D360 (one group consists of at least one primary caregiver and the PLwD) spanning across two counties, Allegheny and Westmoreland. These groups are comprised of people from various backgrounds including age, race/ethnicity, education level, and socioeconomic status.

The majority of caregivers are a spouse/partner to the PLwD representing 64% of the caregiver population, while adult children of the PLwD represent 30%. The remaining 6% is comprised of "other" relationships to the PLwD including a friend or family member. The average caregiver age is 70 years old with a population age range of 32-95 years old. Scores from the Zarit Caregiver Burden assessment range from 2-34 with an average score of 20.

The average age of the PLwD is 82 years old with a population age range of 62-96 years old. Cognitive functionality varies too, with an average MoCA score of 11 with a score range between 0-24. The average ADL score is 15 with a score range between 2-20 and an average IADL score of 1.36 with a score range between 0-5. GDS scores range from 0-11 with an average score of 4. Clinical encounters for the past 12 months are as followed: 33% presented to the emergency department at least once, 42% were hospitalized at least once, 22% were placed then unplaced in

an SNF at least once, and 46% recorded at least one fall. The average number of chronic conditions (not including dementia) is 4 with the number of chronic conditions ranging from 0-12. A comprehensive overview of this data can be found in Appendix C.

### **4.3 Cohort Evaluation**

The first phase of evaluation is done during the initial assessment period. Within this period the care manager will perform one to three home visits to collect preliminary data on the caregiver and PLwD. The care manager is responsible for administering the evaluation, where he/she uses the approved assessment tools to collect qualitative and quantitative data from both the caregiver(s) and PLwD. The tools that are used will be described in detail below. The evaluation processes are standardized to address concerns of data validity. The initial visits last anywhere between one and three hours. Depending on the acuity of the PLwD and the severity of caregiver burden, the initial evaluation period for the PLwD and caregiver can be accomplished in as early as one week and take as long as four weeks.

The second phase of evaluation is done four to six weeks after the initial assessment period and is conducted via phone calls or by email. By this time the caregiver has received a care plan and is assumed to be following the suggestions outlined in the roadmap. The roadmap is comprised of created interventions/solutions to address the barriers and challenges identified during the initial assessment period. The care manager is responsible for gathering input and other suggestions during this time and will work together with the caregiver to adapt the care plan to solve emerging issues or reassess issues that have already been identified. Follow-up caregiver burden assessments will also take place during this time to gauge the effectiveness of the proposed interventions.



Several factors can affect the timeliness of the evaluation process, most notably being attitude and acceptance issues as they relate to the perceived value of the program and overall disease acceptance. After the first and second evaluation phases are completed, the final step is to ensure program maintenance.

#### **4.4 Qualitative Method**

The following sections explain the type of qualitative method used to gather data to form hypotheses about the caregiver's level of burden, current life situation, and overall quality of life. The method below takes place during the initial assessment period. The observations collected can then be used to make appropriate recommendations for current interventions or create new interventions for the future.

##### **4.4.1.1 Caregiver Observations**

During the initial home assessment, the care manager observes the physical environment in which the caregiver and PLwD reside. He/she uses these observations to form hypotheses about possible care barriers and challenges. Some examples include observing the structural integrity of the walking paths and railings to the front door, interior home safety issues such as the lack of non-slip surfaces (rugs, carpet, etc.), as well as other possible risk factors such as poorly placed household items (utensils, important mail, glassware, etc.). Additional to the physical environment, the care manager also observes the behaviors of the caregiver. He/she records notes relating to non-verbal communication, perceived levels of calmness, agitation, or nervousness, the caregiver's actions towards other members in the home (if any others live there), as well as other

actions and observations unique to the care manager's interactions. This information is then used to form a generalization about the caregiver's personality and character, as well as their overall home-life situation. The hypotheses formed during the observations are then used to project the level of adherence to the proposed care plan, the difficulty of the overall case, and whether or not the caregiver is likely to continue throughout the program. Currently, there is no formal repository for this data outside of each client's case file. The collected information is used only on a case-by-case basis to form hypotheses about the caregiver's situation for whom the care manager recorded the observations.

## **4.5 Quantitative Methods**

The following sections explain the types of quantitative methods used to gather data about the caregiver to determine QoL and burden levels. Additionally, the following sections will assess the level of cognitive impairment, mental strain, and physical abilities of the PLwD. The methods below take place during the initial assessment period, with the caregiver QoL questionnaire and burden assessment being reassessed during the follow-up period. The quantitative methods used to assess the PLwD are not reassessed. Dementia is a progressive disease so we expect these initial data points to scale down over time.

### **4.5.1.1 Caregiver Quality of Life Questionnaire**

The care manager provides set questions which the caregiver offers scaled responses to. These questions range from perceived psychological and physiological challenges to perceived difficulty engaging in caregiving activities versus leisure activities. The first section within this

questionnaire assesses the caregiver's health, habits, stress, and perceived overload. There are 10 total questions with a rating scale range from 1-4, with lower scores being associated with a positive lifestyle for questions 3, 4, 6, 7, 8, 9, and 10. Higher scores are associated with a negative lifestyle for questions 1, 2, and 5. Lower summed scores for questions 3, 4, 6, 7, 8, 9, and 10 are associated with better control over one's life and attributed to less likelihood of caregiver burnout, while higher summed scores for questions 1, 2, and 5 are the opposite.

The second portion of the questionnaire assesses the caregiver's perceived ability to care for the PLwD. The rating scales range from 1-10 with higher scores being associated with better control over one's caregiving situation. Afterward, the caregiver is asked to rate their overall perceived QoL on a scale of 0-100. Extreme ranges are especially noted (0-10; 90-100) and may warrant follow-up questions depending upon the results of the overall assessment.

The final portion of the questionnaire makes inquiries about the financial burden associated with caregiving. This section is aimed at assessing the caregiver's perceived financial situation so that the care manager can create appropriate interventions and compile financially feasible service suggestions that fit within the caregiver's means.

After assessing the answers provided by the caregiver, the care manager will then determine the overall quality of life score by analyzing the breakdown of the answers given relative to their scoring criteria.

#### **4.5.1.2 Montreal Cognitive Assessment (MoCA)**

This comprehensive screening tool is used to determine the level of cognitive impairment among those living with dementia and Alzheimer's. The MoCA was created in 1995, by Dr. Ziad Nasreddine in Montreal, Canada, and has since been used by various health professionals in LTCs and hospitals, as well as by researchers in universities and public health institutes. For this

assessment to produce reliable results, the test administrator must undergo basic training to avoid gathering biased answers. The training consists of proper administering techniques as well as rules to follow to score appropriately. Currently, the care manager administers this assessment during the initial assessment period. The test is broken down into eight sections and assigns an overall score upon completion. The tool assesses six different functionalities of cognition including, executive function, attention, abstraction, short-term memory, language abilities, and orientation. Each category is scored separately and makes up a certain portion of the final grade. The final grade is then used to determine the overall severity of dementia. Scores range from 0-30, with lower scores associated with higher severity of the disease. The following breakdown below outlines the possible MoCA scores and associated severity grade:

*$\geq 26/30$ : No Dementia*

*18-25/30: Mild Cognitive Impairment*

*11-17/30: Mild Dementia*

*6-10/30: Moderate Dementia*

*$< 6/30$ : Severe Dementia*

#### **4.5.1.3 Geriatric Depression Scale (GDS)**

This tool provides an overview of the level of mental strain experienced by the PLwD. The GDS was developed in 1982 by J.A. Yesavage in order to test for signs of depression symptoms among older adults. While this test is slightly similar to assessments used in adolescence for depression diagnoses, the GDS's purpose is not to be used as a clinical diagnostic tool alone. Currently, the care manager uses this tool during the initial assessment period. The test is broken down into fifteen different YES/NO questions which assess areas such as level of enjoyment, overall interests in life, social interactions, among several others. Scoring this test is done by

awarding a point towards each question answered that indicates depression. A point is awarded if answered “YES” for questions, 2, 3, 4, 6, 8, 9, 10, 12, 14, and 15 or if answered “NO” for questions, 1, 5, 7, 11, and 13. Total scoring is done by adding up all of the awarded points to determine an overall score. The following breakdown below outlines the possible GDS scores relative to the level of depression symptoms:

*= 0: No depression symptoms*

*1-5: Mild depression symptoms*

*> 5: Severe depression symptoms*

#### **4.5.1.4 Barthel Activities of Daily Living (ADL)**

This assessment provides an overview of the person’s abilities to complete regular activities that contribute to daily living. Some competencies the test measures are toileting, bathing, grooming, mobility, among several others. The competencies are then further broken down into specific sections which are then scored on a scale of 0-3. A score of 0 corresponds to the inability to do the activity, while a score of 3 corresponds to the complete ability to perform the activity independently. The section scores are then added up to make an overall ADL score. The total score is then used to determine the level of independence a PLwD has with regard to completing regular daily activities.

#### **4.5.1.5 Lawton Brody Instrumental Activities of Daily Living (IADL)**

This assessment is used in conjunction with the ADL screening tool to assess a person’s overall ability to function independently. Similar to the ADL tool, the Lawton Brody IADL assessment gauges the level of independence a PLwD has with regard to completing daily living activities. However, the major difference is that the IADL tool assesses the person’s ability to

perform more comprehensive tasks rather than simple tasks. Some of the tested categories are the ability to use the telephone, the ability to handle personal finances, responsibility for own medication use, among several others. The scoring scale ranges from 0-1. A score of 0 indicates the person is dependent on others to perform the activity, while a score of 1 indicates independence. Scores of 1 are further broken down into levels of independence – some independence, moderate independence, and complete independence.

#### **4.5.1.6 Zarit Caregiver Burden Assessment (Abridged)**

This assessment tool measures the overall severity of burden attributed to caregiving for someone living with dementia. There are 12 questions in total with a scaled rating for each question ranging from 0-4. Higher indications of burden are recorded in responses 2 or higher. Each question is then summed to create a total score which is then used to interpret overall caregiver burden and predict burnout. Summed scores can range from 0-48, with higher scores being associated with higher levels of caregiver burden. The interpretation of summed scores is outlined below:

*0-10: Little or no burden*

*11-20: Mild to moderate burden*

*> 20: Severe burden*

## **5.0 Recommendations**

D360 attempts to accomplish its goals of managing the caregiver and PLwD by offering several solutions considered to be “best practices”. There can be an exhaustive list, as all caregiving situations are unique, however, the sections to follow will outline the five commonly recommended care management solutions with regard to caring for a community-based caregiver population (Beinart, Weinman, Wade, & Brady, 2012).

### **5.1.1 Dementia Education**

The most widely used intervention is the provision of dementia education to the primary (and potentially secondary) caregiver. This is considered to be one of the foundations of disease acceptance as it educates the caregiver on what is physiologically occurring to their loved one. After the initial assessment period, the caregiver receives a binder complete with dementia-specific education materials related to the type of dementia the PLwD received a diagnosis for. Some of the documents included in the binder explain physical and behavioral symptoms of the disease, the rate of normal disease progression, solutions to alleviate everyday challenges, along with other supporting documents describing the outlook for the next few years. All dementias are different so it is crucial the caregiver be knowledgeable of the symptoms and behaviors that go along with their loved one’s diagnosis. Education about the disease not only decreases possible anger towards the PLwD, but it also helps to explain some of the behaviors they exhibit. This helps the caregiver learn that the behaviors are not associated with the person’s temperament but instead the result of

disease progression. This can help relieve stress felt by the caregiver and also decreases the likelihood of blaming and retaliating.

### **5.1.2 Stress Management**

A crucial component to avoid fostering and exhibiting negative caregiving feelings is through stress management. Caring for someone who is chronically ill can be a demanding task, especially when there is no current chance of recovery. Quickly the situation can turn into a demoralizing burden that will only harm the mental and physical health of the caregiver along with place strain on the relationship with the PLwD. Increased caregiving stress not only affects how care is provided but also the quality of care as well. For this reason, it is imperative to develop stress management techniques and follow the necessary steps to mitigate any stressful situation before it festers. The way D360 aims to solve this problem is by compiling and creating stress management resource guides to assist the caregiver through daily challenges. These interventions are developed specifically from the caregiver's initial assessment and are adapted as the caregiving situation becomes more challenging. All of the techniques included in the stress management plan share competencies to deal specifically with behavioral, physical, and emotional stress and the consequences that come with them. The recommendations are normally researched and compiled from internationally recognized dementia and Alzheimer's research institutions such as the Alzheimer's Association, Centers for Disease Control and Prevention, and the World Health Organization. In some circumstances, the caregiving burden may become too much to bear. In this case, the care manager will make the appropriate decision to connect the caregiver with psychological resources.



### **5.1.3 Support Group Connection**

Providing support groups has been shown to be a low-cost, effective way of reducing some of the burden associated with constant caregiving. This holds especially true for family caregivers and those new to caregiving entirely (Grässel, Trilling, Donath, & Luttenberger, 2010). Specific support groups exist for a multitude of issues and can be a much-needed resource to alleviate the feelings of social isolation and helplessness (Johnson & Maguire, 1989). PSCN realizes the importance of offering this service and attempts to make the resource more accessible and less stigmatized by creating their own personalized support group for their D360 enrollee population, which they call the Memory Cafe. By doing this, members within the program have the chance to meet each other and talk about their successes and challenges concerning caregiving and care management service options. This support group is also unique in encouraging both the caregiver and PLwD to attend so that not only the caregiver benefits from social interaction but the PLwD does as well. Being that the program enrolls a variety of caregivers across two counties, it is important to realize that not everyone enrolled in the program can attend. In this case, the care manager will suggest and connect those individuals with the other support groups that exist within the greater Pittsburgh region that may make travel more geographically reasonable. Some examples include those at various health system facilities, churches, community centers, along with others sponsored by local long-term care networks.

### **5.1.4 Respite Care Options**

Taking a break from caregiving duties can make an enormous impact on the mental and physical health of the caregiver and is proven to be an effective tool when predicting caregiver

resilience throughout the continuum of caregiving (Roberts & Struckmeyer, 2018). One of the early predictors of caregiver burnout is neglecting to take time for one's self or not having the opportunity due to the complexity of the PLwD's situation. D360 aims to mitigate this major issue by offering several caregiver respite solutions in order to alleviate the continuous stress. Two of the main options that are often suggested are companion programs and adult daycare. Many of the program enrollees have opted to pursue these options to free-up some of their time to do necessary and leisure activities. Recently, PSCN has partnered with the Area Agency on Aging for Allegheny County to provide a program called *Senior Companions*. This adult companion program matches the caregiver and PLwD with a senior volunteer that is capable of providing a friendly visit to the home to engage the PLwD in various stimulating activities and conversation. This service allows the caregiver to take some time off from regular caregiving duties to pursue leisure activities or run errands. Another respite option regularly suggested is the adult daycare service that is offered at PSCN-Woodside Place. The PLwD can spend up to eight hours at the facility and is surrounded by an experienced staff that engages them in various physically and mentally stimulating activities. Additionally, this service provides the daycare goes with meals and offers other benefits such as bathing and changing of clothes, which can sometimes be a major struggle for caregivers. Other adult daycare programs exist outside of PSCN and are referred to those caregivers that live further away from the Oakmont area. It is important to note that the aforementioned respite services are rarely free except for the volunteer companion program, which still has its downsides as the wait time to receive a volunteer could take up to a month.

### **5.1.5 In-Home Care**

These services are often suggested if the caregiver has strict personal and professional obligations that inhibit them from spending adequate time with the PLwD. The fees associated with in-home care can range from \$20-\$30 an hour depending on the agency that is used. There are currently several agencies in the Pittsburgh area that offer in-home care services for all acuity levels. Depending on the caregiver's schedule, an in-home care visit can last from a few hours to a full day. Some agencies offer nurses as in-home care aids that are more expensive, however, this allows the PLwD to receive clinical care as well as daily supervision and assistance. One of the major critiques and challenges surrounding this option is the cost associated with sustained utilization. These services cost on average \$53,000 annually depending on the frequency of use (Genworth, 2020). For that reason, this care option is relatively unsustainable for the majority of our client population enrolled in the program. Since these services are rarely (if not at all) covered by insurance, the majority of caregivers will have to pay the expenses out-of-pocket. Coupled with the other potentially increasing costs associated with general caregiving (E.D. visits, higher acuity care needs, increased care services costs, etc.), along with a potential decrease in job pay due to time off, the expenses associated with in-home services are rarely feasible for the average caregiver. However, these services are still being sought out on an acute-style basis, meaning the use is sporadic and lasts only a day or two out of the week. Additionally, this care option continues to be popular among D360's wealthier clients, given they have a higher risk tolerance concerning financial burden.

## **6.0 Summary**

D360 aims to decrease the negative physiological and psychological symptoms associated with caregiver burden by offering the five above recommendations to its enrollee population. Each intervention draws upon a specific caregiving need that addresses topics such as education, relaxation, and care assistance. These recommendations are the foundation of the individual's care plan and represent the most recognized managed care solutions to addressing caregiver burden. The aforementioned recommendations are the most highly utilized resources among D360's enrollee population, with 100% of all caregivers using at least two or more of the five total interventions.

## **6.1 Discussion**

After conducting a year's worth of research and analysis, the top five recommendations were ultimately identified and modeled after best-practice interventions outlined by relevant literature, disease-specific expertise from PSCN and the Alzheimer's Association, and estimated effectiveness based upon the program's enrollee population. It is important to note the recommendations above account only for a small portion of the total D360 program offerings, which continues to grow exponentially on a case by case basis. While there is an exhaustive list, it would be inappropriate to include all suggested interventions as they lack the generalizability compared to those highlighted in the previous sections. Furthermore, the specificity of each caregiver's scenario will be different from the other as well, making it impossible to standardize

one individual's care plan and expect it to bring value to the entire population. Instead, D360 focuses on providing each caregiver with an initial package comprised of dementia education, stress management techniques, support group connections, respite care options, and in-home care options—all of which are proved to be useful among the general caregiver population in some capacity. After these initial recommendations are made comes the supplementation of other resources tailored to the caregiver's situation. Through this strategy, the program achieves maximum caregiver value, while also providing the care managers with an efficient resource gathering process.

## **7.0 Conclusion**

Dementia and Alzheimer's disease continue to prove to be a challenging health issue as public health officials are just beginning to realize the sheer nature of this highly misunderstood disease. Unlike infectious diseases, effective solutions for the challenges associated with memory disorder require an individualized approach. The impacts related to disease progression are experienced and perceived differently too, making successful care delivery an involved process dependent upon each individual's unique situation as it relates to their position within the socio-economic pyramid. Researchers, public health institutions, and not-for-profit organizations have all helped make significant steps towards bettering the lives of caregivers and PLwD through research and evidence-based programs. However, this problem still proves to be a major challenge for underserved populations that have minimal resources and lack of care access. Because of this, greater importance is beginning to be placed on community-based care models as they have shown success in managing other related chronic health conditions in a home setting.

Based on the literature outlined in this paper, and after assessing the components of PSCN's community-based managed care model for addressing Alzheimer's and other related dementias, the goal of maintaining successful disease management within a specific population is possible.

## **7.1 Limitations**

PSCN cannot predict the true cost/benefit analysis of the program outside of general estimations based upon examples of managed care programs within the country. D360 currently

provides all of its services free of charge and will move to a fee-for-service model following the end of the grant-funded period December 31, 2020. The program has started to collect health insurance information from its enrollees to process “sample invoices”, which it will use to gauge the effectiveness of its billing processes post-transition. A comprehensive report on the status of this trial run could not be obtained and was thus unable to be discussed in this paper. PSCN expects the collection of financial performance data related to D360 operations to begin in the year 2021.

Preliminary data collected during the early stages of program development and post-launch are rudimentary and cannot be used in a formal program analysis outside of benchmarking and trend spotting. A more consistent data collection process was established in April 2019.

The program will continue to improve upon the data collection process as it phases out of the grant funding stage and into a reimbursement model. Standardization is estimated to be achieved by December 2020.

## **Appendix A Caregiver Assessment Tools**

The documents below are samples of the quantitative tools used to assess the caregiver. All documents are copyrighted property of Presbyterian SeniorCare Network.



## Appendix A.1 Caregiver Quality of Life Questionnaire

### ***Caregiver Health Habits, Stress, and Overload:***

*In the past month, how often have these statements been true for you?*

	None of the time	Some of the time	Most of the time	All of the time	
I got an adequate amount of sleep.	1	2	3	4	
I got an adequate amount of exercise.	1	2	3	4	
	None of the time	Some of the time	Most of the time	All of the time	
I ate a healthy, balanced diet.	1	2	3	4	
When I felt sick, I took appropriate care of myself.	1	2	3	4	N/A
I drank more alcohol than I should.	1	2	3	4	
I ate too much or too little.	1	2	3	4	
I found time just to relax.	1	2	3	4	
I wish I were free to lead a life of my own	1	2	3	4	
I wish I could just run away.	1	2	3	4	
I feel trapped by my loved one's illness.	1	2	3	4	
I am exhausted when I go to bed at night.	1	2	3	4	
I have more things to do than I can handle.	1	2	3	4	

1. How confident are you that you have the skills you need to help care for your loved one?

0            1            2            3            4            5            6            7            8            9            10

Not at all confident

Certain I can do it

2. How confident are you that you are able to take care of your own personal needs while caring for your loved one?

0            1            2            3            4            5            6            7            8            9            10

Not at all confident

Certain I can do it

3. How confident are you that you will be able to continue to help your loved one stay at home?

0            1            2            3            4            5            6            7            8            9            10

Not at all confident

Certain I can do it

4. How would you rate your overall physical health at the present time?

Poor

Fair

Good

Excellent

5. How would you rate your physical health compared to what it was 1 year ago?

Much Worse

A Little Worse

About the Same

A Little Better

Much Better

6. On a scale of 1 to 100, with 1 being terrible and 100 being perfect, how would you rate your overall quality of life? And why do you say that?

*The next questions ask you to consider the financial impact of caregiving. Please circle the response that is most closely related to your situation.*

1. In general, how do finances work out at the end of the month? Do you usually have:

Some money left over

Just enough to make ends meet

Not enough to make ends meet

2. Do you consider the money you have to spend on the person for whom you are caregiving to be:

*Much* more than you can afford

Somewhat more than you can afford

About what you can afford

Not applicable – I am not financially responsible for paying for caregiving needs

## Appendix A.2 Zarit Caregiver Burden Assessment

*The next questions ask about the impact of caregiving on your life... please circle the best response:*

Do you feel....	0	1	2	3	4
That because of the time you spend with your relative one you don't have enough time for yourself?	Never	Rarely	Sometimes	Quite frequently	Always
Stressed between caring for your relative and trying to meet other responsibilities (work/family)?	Never	Rarely	Sometimes	Quite frequently	Always
Angry when you are around your relative?	Never	Rarely	Sometimes	Quite frequently	Always
That your relative currently affects your relationship with family or friends in a negative way?	Never	Rarely	Sometimes	Quite frequently	Always
Strained when you are around your relative?	Never	Rarely	Sometimes	Quite frequently	Always
That your health has suffered because of your involvement with your relative?	Never	Rarely	Sometimes	Quite frequently	Always
That you don't have as much privacy as you would like because of your relative	Never	Rarely	Sometimes	Quite frequently	Always
That your social life has suffered because you are caring for your relative?	Never	Rarely	Sometimes	Quite frequently	Always
That you have lost control of your life since your relative's illness?	Never	Rarely	Sometimes	Quite frequently	Always
Uncertain about what to do about your relative?	Never	Rarely	Sometimes	Quite frequently	Always
You should be doing more for your relative?	Never	Rarely	Sometimes	Quite frequently	Always
You could do a better job in caring for your relative?	Never	Rarely	Sometimes	Quite frequently	Always

## **Appendix B PLwD Assessment Tools**

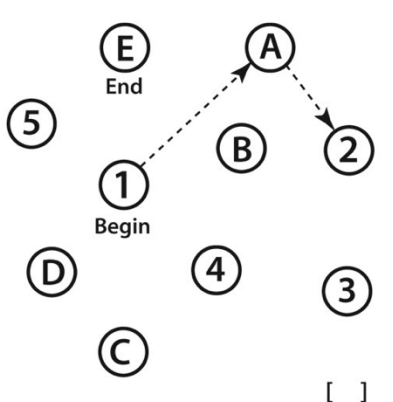
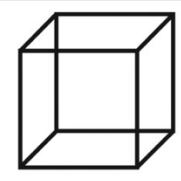
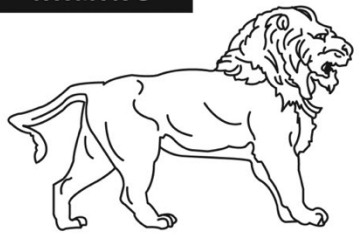
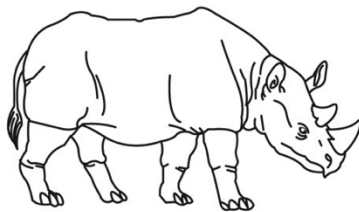
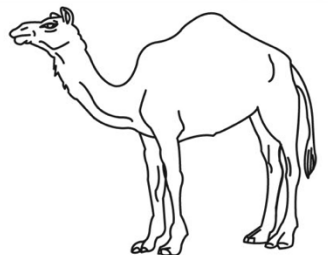
The documents below are samples of the quantitative methods used to assess the PLwD. All documents are copyrighted property of Presbyterian SeniorCare Network with exception of the Montreal Cognitive Assessment (MoCA), which can be found, downloaded, and used freely by the public domain.

## Appendix B.1 Montreal Cognitive Assessment (MoCA)

**MONTREAL COGNITIVE ASSESSMENT (MOCA)**  
Version 7.1 Original Version

NAME :  
Education :  
Sex :

Date of birth :  
DATE :

VISUOSPATIAL / EXECUTIVE		NAMING		MEMORY		ATTENTION		LANGUAGE		ABSTRACTION		DELAYED RECALL		Optional		ORIENTATION		POINTS																																																						
 <div style="display: flex; justify-content: space-around; margin-top: 10px;"> <span>[ ]</span> <span>[ ]</span> </div>		 <div style="margin-top: 10px;"> <span>[ ]</span> </div>		<p>Draw CLOCK (Ten past eleven) (3 points)</p> <div style="display: flex; justify-content: space-around; margin-top: 10px;"> <span>[ ]</span> <span>[ ]</span> <span>[ ]</span> </div>		<div style="display: flex; justify-content: space-around; margin-top: 10px;"> <span>[ ]</span> <span>[ ]</span> <span>[ ]</span> </div>		<div style="display: flex; justify-content: space-around; margin-top: 10px;">    </div> <div style="display: flex; justify-content: space-around; margin-top: 10px;"> <span>[ ]</span> <span>[ ]</span> <span>[ ]</span> </div>		<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td></td> <td>FACE</td> <td>VELVET</td> <td>CHURCH</td> <td>DAISY</td> <td>RED</td> </tr> <tr> <td>1st trial</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>2nd trial</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>			FACE	VELVET	CHURCH	DAISY	RED		1st trial						2nd trial						<p>Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [ ] 2 1 8 5 4</p> <p>Subject has to repeat them in the backward order [ ] 7 4 2</p>		<p>Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors</p> <p>[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B</p>		<p>Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65</p> <p>4 or 5 correct subtractions: <b>3 pts</b>, 2 or 3 correct: <b>2 pts</b>, 1 correct: <b>1 pt</b>, 0 correct: <b>0 pt</b></p>		<p>Repeat : I only know that John is the one to help today. [ ]</p> <p>The cat always hid under the couch when dogs were in the room. [ ]</p>		<p>Fluency / Name maximum number of words in one minute that begin with the letter F [ ] ____ (N ≥ 11 words)</p>		<p>Similarity between e.g. banana - orange = fruit [ ] train - bicycle [ ] watch - ruler</p>		<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td></td> <td>FACE</td> <td>VELVET</td> <td>CHURCH</td> <td>DAISY</td> <td>RED</td> <td rowspan="3">Points for UNCUED recall only</td> </tr> <tr> <td>Has to recall words <b>WITH NO CUE</b></td> <td>[ ]</td> <td>[ ]</td> <td>[ ]</td> <td>[ ]</td> <td>[ ]</td> </tr> <tr> <td>Category cue</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Multiple choice cue</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>			FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUED recall only	Has to recall words <b>WITH NO CUE</b>	[ ]	[ ]	[ ]	[ ]	[ ]	Category cue						Multiple choice cue							<p>[ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City</p>	
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[www.mocatest.org](http://www.mocatest.org)

Normal ≥ 26 / 30

Administered by: \_\_\_\_\_

## Appendix B.2 Geriatric Depression Scale (GDS)

Are you basically satisfied with your life?	Yes	No
Have you dropped many of your activities and interests?	Yes	No
Do you feel your life is empty?	Yes	No
Do you often get bored?	Yes	No
Are you in good spirits most of the time?	Yes	No
Are you afraid something bad is going to happen to you?	Yes	No
Do you feel happy most of the time?	Yes	No
Do you often feel helpless?	Yes	No
Do you prefer to stay at home rather than going out and doing things?	Yes	No
Do you feel you have more problems with your memory than most?	Yes	No
Do you think it is wonderful to be alive now?	Yes	No
Do you feel worthless the way you are now?	Yes	No
Do you feel full of energy?	Yes	No
Do you feel your situation is hopeless?	Yes	No
Do you think that most people are better off than you are?	Yes	No

Award a point for each answer of "YES" on questions 2, 3, 4, 6, 8, 9, 10, 12, 14, and 15 or an answer of "NO" on questions 1, 5, 7, 11, and 13.

Scores of 0 indicate no depression symptoms, scores between 1-5 indicates mild depression symptoms, and scores greater than 5 indicate severe depression symptoms.

## Appendix B.3 Barthel Activities of Daily Living (ADLs)

### Activities of Daily Living

Instructions: Please circle the statement that is closest to the current level of ability for the person for whom you are caregiving. **Be sure to record current function (what he or she is ACTUALLY doing, not what he or she could potentially do).**

<b>Bowels</b>	Incontinent (or needs to be given enema) 0	Occasional accident (1x/week) 1	Continent 2	
<b>Bladder</b>	Incontinent or catheterized and unable to manage 0	Occasional accident (max 1x per 24 hours) 1	Continent 2	
<b>Grooming</b>	Needs help with personal care 0	Independent with face/hair/teeth/shaving if you provide what is needed 1		
<b>Toilet Use</b>	Dependent 0	Needs some help but can do something alone 1	Independent with getting on and off, dressing, wiping 2	
<b>Feeding</b>	Unable 0	Needs help cutting, spreading butter, etc. 1	Independent if you put food within reach 2	
<b>Transfer</b>	Unable (can't sit on own) 0	Needs physical help from 1 or 2 people, can sit on own 1	Needs minor help – verbal or physical 2	Independent 3
<b>Mobility</b>	Immobile 0	In a wheelchair but independent in it, including going around corners, etc. 1	Walks with verbal or physical help of 1 person 2	Independent, may use assistive device 3
<b>Dressing</b>	Dependent 0	Needs help but can do about half unaided 1	Independent including buttons, zippers, laces, etc. 2	
<b>Stairs</b>	Unable 0	Needs help (verbal, physical, or assistive device) 1	Goes up and down stairs independently 2	
<b>Bathing</b>	Dependent 0	Independent (can wash self and get in and out without help or supervision) 1		

Total: \_\_\_\_\_

## Appendix B.4 Lawton Brody Instrumental Activities of Daily Living (IADLs)

### Instrumental Activities of Daily Living

Instructions: Please circle the statement that is closest to the level of ability for the person for whom you are caregiving. Different than the last set of questions, **please circle what he or she CAN do rather than what he or she is doing.**

<b>Ability to use telephone</b>	Uses on own initiative; can look up and dial numbers 1	Dials a few well known numbers 1	Answers telephone but does not dial 1	Does not use telephone at all 0	
<b>Shopping</b>	Takes care of all shopping needs independently 1	Shops independently for small purchases 0	Needs to be accompanied on any shopping trip 0	Completely unable to shop 0	
<b>Food preparation</b>	Plans, prepares, serves adequate meals independently 1	Prepares adequate meals if supplied with ingredients 0	Heats/ serves prepared meals or prepares meals but does not maintain adequate diet 0		Needs to have meals prepared and served 0
<b>Housekeeping</b>	Maintains house alone with occasional assistance (heavy work) 1	Performs light daily tasks such as dishwashing, bed making 1	Performs light tasks but cannot maintain acceptable level of cleanliness 1	Needs help with all home maintenance tasks 1	Does not participate in any housekeeping tasks 0
<b>Laundry</b>	Does personal laundry completely 1		Launders small items, rinses socks, stockings, etc. 1		All laundry must be done by others 0
<b>Mode of transportation</b>	Drives own car or travels independently on public transportation 1	Arranges own travel via taxi but otherwise does not use public transport 1	Travels on public transport when assisted/ accompanied 1	Travel limited to taxi or car with assistance of another 0	Does not travel at all 0
<b>Responsibility for own medications</b>	Responsible for taking medication in correct dosage and at correct time 1		Takes responsibility if medication is prepared in advance in separate doses 0		Is not capable of dispensing own meds 0
<b>Ability to handle finances</b>	Manages financial matters independently (budgets, writes checks, pays bills, goes to bank) collects and tracks income 1		Manages day to day purchases but needs help with banking, major purchases, etc. 1		Cannot handle money 0

Total: \_\_\_\_\_



## Appendix C Dementia360 Year 1 Program Summary



# Year 1 Summary Dashboard

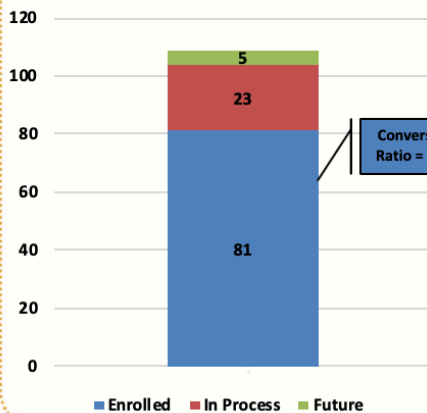
Data updated through January 31, 2020

**Projected vs. Actual Enrollment**

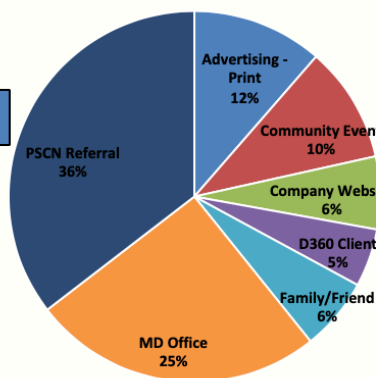
	2019				2020
	Q1	Q2	Q3	Q4	Q1
Projected new enrollments per Quarter	16	27	27	27	27
Projected Exits (5%)	1	2	3	5	6
Projected Cumulative Net Enrollment	15	40	64	86	107
Actual Cumulative Enrollments	15	35	62	83	97
Actual Exits	0	0	7*	12*	16*
Actual Cumulative Net Enrollment	15	35	55	71	81

Definition of Enrollment: Clients who have signed a contract

\*5 exits due to death, 9 due to placement, 2 unable to reach



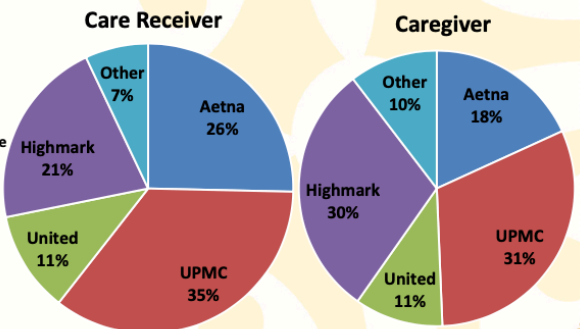
**Enrollment Sources**



Caregiver Characteristics (n=81)	
Spouse of care recipient	52 (64%)
Adult child of care recipient	24 (30%)
Other relationship	5 (6%)
Average age	70 (range 32-95)

Care Recipient Characteristics (n=81)	
Avg. age	82 (range 62-96)
Avg. MoCA score	11 (range 0-24)
Avg. ADL score	15 (range 2-20)
# who had ED visits/12 mo.	27 (33%)
# hospitalized/12 mo.	34 (42%)
# who had SNF stays/12 mo.	18 (22%)
# who had falls/12 mo.	37 (46%)
Avg. # of chronic conditions (not including dementia)	4 (range 0-12)

**Payer Types**



## Bibliography

- Alzheimer's Association. (2019). *2019 Alzheimer's Disease Facts and Figures* [PDF file]. Retrieved from <https://www.alz.org/media/documents/alzheimers-facts-and-figures-2019-r.pdf>
- Alzheimer's Disease International. (2015). Dementia statistics. Retrieved from <https://www.alz.co.uk/research/statistics>
- Avent, E. S., Rath, L., Meyer, K., Benton, D., & Nash, P. (2019). Supporting Family Caregivers: How Does Relationship Strain Occur in Caregiving Dyads? A Qualitative Study. *Innovation in Aging*, 3(Suppl 1), S289. <https://doi.org/10.1093/geroni/igz038.1066>
- Bass, D. M., Clark, P. A., Looman, W. J., McCarthy, C. A., & Eckert, S. (2003, February). Cleveland Alzheimer's Managed Care Demonstration: Outcomes After 12 Months of Implementation. Retrieved from <https://doi.org/10.1093/geront/43.1.73>
- Beinart, N., Weinman, J., Wade, D., & Brady, R. (2012). Caregiver burden and psychoeducational interventions in Alzheimer's disease: a review. *Dementia and geriatric cognitive disorders extra*, 2(1), 638–648. <https://doi.org/10.1159/000345777>
- Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in clinical neuroscience*, 11(2), 217–228. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181916/>
- Cheng, S. Dementia Caregiver Burden: a Research Update and Critical Analysis. *Curr Psychiatry Rep* 19, 64 (2017). <https://doi.org/10.1007/s11920-017-0818-2>
- Fox, P. D., & Kongstvedt, P. R. (2013). A history of managed health care and health insurance in the United States. *Essentials of managed health care. Burlington, Sixth Edition: Jones & Bartlett Learning*. Retrieved from <http://samples.jbpub.com/9781449653316/Chapter1.pdf>
- Genworth. (2020, March). Median Cost of Nursing Home, Assisted Living, & Home Care. Retrieved from <https://www.genworth.com/aging-and-you/finances/cost-of-care/cost-of-care-trends-and-insights.html>
- Grassel, E., Trilling, A., Donath, C., & Luttenberger, K. (2010). Support groups for dementia caregivers--predictors for utilisation and expected quality from a family caregiver's point of view: a questionnaire survey part I\*. *BMC health services research*, 10, 219. <https://doi.org/10.1186/1472-6963-10-219>
- Institute of Medicine (US) Committee on Assuring the Health of the Public in the 21st Century. The Future of the Public's Health in the 21st Century. Washington (DC): National

- Academies Press (US); 2002. 5, The Health Care Delivery System. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK221227/>
- Johnson, M., & Maguire, M. (1989, November 1). Give Me A Break: Benefits of a Caregiver Support Service. Retrieved from <https://www.healio.com/nursing/journals/jgn/1989-11-15-11/{0990f71e-9722-408f-a097-7745b103e733}/give-me-a-break-benefits-of-a-caregiver-support-service>
- LaMarre A.K., Kramer J.H. (2019) Assessment of Behavioral Variant Frontotemporal Dementia. In: Ravdin L., Katzen H. (eds) Handbook on the Neuropsychology of Aging and Dementia. Clinical Handbooks in Neuropsychology. Springer, Cham. [https://doi.org/10.1007/978-3-319-93497-6\\_33](https://doi.org/10.1007/978-3-319-93497-6_33)
- Malonebeach, E. E., Zarit, S. H., & Spore, D. L. (1992). Caregivers' Perceptions of Case Management and Community-Based Services: Barriers to Service Use. *Journal of Applied Gerontology*, 11(2), 146–159. <https://doi.org/10.1177/073346489201100202>
- National Institute on Aging. (2017, May 17). End-of-Life Care for People with Dementia. Retrieved from <https://www.nia.nih.gov/health/end-life-care-people-dementia#progression>
- Roberts, E., & Struckmeyer, K. M. (2018). The Impact of Respite Programming on Caregiver Resilience in Dementia Care: A Qualitative Examination of Family Caregiver Perspectives. *Inquiry: a journal of medical care organization, provision and financing*, 55, 46958017751507. <https://doi.org/10.1177/0046958017751507>
- Samus, Q. M., Black, B. S., Bovenkamp, D., Buckley, M., Callahan, C., Davis, K., Gitlin, L. N., Hodgson, N., Johnston, D., Kales, H. C., Karel, M., Kenney, J. J., Ling, S. M., Panchal, M., Reuland, M., Willink, A., & Lyketsos, C. G. (2018). Home is where the future is: The BrightFocus Foundation consensus panel on dementia care. *Alzheimer's & dementia: the journal of the Alzheimer's Association*, 14(1), 104–114. <https://doi.org/10.1016/j.jalz.2017.10.006>
- Schulz, R., Beach, S. R., Czaja, S. J., Martire, L. M., & Monin, J. K. (2020, January). Family Caregiving for Older Adults. Retrieved from <https://www.annualreviews.org/doi/abs/10.1146/annurev-psych-010419-050754>
- Swartz, K., & Collins, L. G. (2019). Caregiver care. *American family physician*, 99(11), 699-706. Retrieved from <https://www.aafp.org/afp/2019/0601/p699.html>
- World Health Organization. (2019, September 19). Dementia. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/dementia>